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Barriers To Screening:

A Critical Review of the Literature (1990-1995)

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A Critical Review of The Literature (1990-1995)

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Preface

The literature on screening in nine subject areas from 1990 to 1995 was reviewed in order to assess the state of current knowledge and identify areas needing additional research. A few review articles were identified, but none which dealt with such a broad cross-section of subjects. We limited ourselves to this time frame and to English language articles because of the time and resource limitations under which we worked and because we believed that the most current literature would reflect the progress up to 1990. Thus, this document is not intended to provide a complete review of all literature related to barriers to screening, but it provides an overview of the existing literature and identifies the common themes that emerged during that review. While we recognize that there are limitations to this study, we found the process extremely enlightening and hope that others will find our report useful.

In general, the health behaviour research of the 1980's provided a substantive body of knowledge that has been applied in many settings. Furthermore, the field of health promotion has advanced our understanding of the determinants of health and the need for multidisciplinary research and multifaceted interventions to enable populations to improve their health status. In this report we identify the theoretical frameworks and models that guide research on screening behaviours. Based upon the literature review, barriers to screening at the individual and systemic levels were identified for each of nine health conditions. The methodological issues that arose from this review are identified and the needs for future research are then discussed.

Common themes in the existing research included the failure to use theory as a basis for research or interventions. Although research related to breast and cervical cancer was more frequently grounded in theory, the majority of studies still failed to identify the behavioral theory on which their study of health behaviours was based. This lack of theoretical development extended to the variables that were selected to represent barriers. Although some consistency was noted in the studies, different studies tended to measure barriers to screening in different ways. Surveys were the most frequently used design. Regardless of the subject area, systemic barriers appeared to play a more substantial role than individual barriers.

Our conclusions can be summarized as follows: no barriers can be classified as well explicated and, therefore, the need for collaborative and multidisciplinary research based on the principles of health promotion is great.

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Section I
Underlying Theoretical Models or Frameworks

I Introduction

This chapter will discuss the use of theories and theoretical models or frameworks in the literature regarding barriers to screening in each of nine subject areas. This will be followed by an overall summary which identifies the strengths, limitations and opportunities for use of these theories and models or frameworks.

A theory, as defined by Kerlinger (cited in Glanz, Lewis, & Rimer, 1990, p.21) is "a set of interrelated constructs (concepts), definitions, and propositions that present a systematic view of the phenomena by specifying relations among variables, with the purpose of explaining and predicting the phenomena". "By telling us about the what, how, when, and why, theories can inform programs" (Glanz, Lewis, & Rimer, 1990, p.21). The term theory is often used to describe what is actually a model or a framework. While this distinction may have little salience for practitioners, if research is going to advance the development of knowledge that is useful in practice, attention must be paid by researchers to making sense of multiple and complex variables, that is the work of theory development. Further, the greatest advances in knowledge will be achieved when researchers and practitioners collaborate.

II Overview of Literature by Type of Screening

A Breast Cancer

Bandura (cited in Glanz, Lewis, & Rimer, 1990, p.22) states that "theories, are interpreted in different ways depending on the stage of development of the field of study. In advanced disciplines, theories integrate laws; in less advanced fields, theories specify the determinants governing the phenomena of interest." Glanz, Lewis, and Rimer (1990) indicate that the latter definition of theory must be used to describe work in the area of health behaviours because the field is still relatively young.

Few of the articles reviewed for this report identified the use of theories, models or frameworks as the basis of their discussion of health behaviours. When a theoretical foundation was identified, the most commonly used model was the HBM (Health Belief Model) (see Appendix A). However, there was little consistency in the utilization of this model. Although the HBM consists of five basic dimensions (perceived susceptibility, perceived severity, perceived benefits and perceived barriers and health motivation) (Rosentock, Strecher, & Becker, 1988, p. 175), some researchers measured additional dimensions under the banner of the HBM.

In addition to the inclusion of unvalidated health belief dimensions, the operationalization of each dimension of the HBM varied between studies. Table 1 shows eighteen different constructs and the extent of their use in nine different studies of barriers to screening behaviours related to breast cancer which explicitly stated that a model was being used. For example, while Zapka, Harris, Stoddard and Constanza (1991) used cost of mammogram, feelings of embarrassment, fear of pain, and worry about radiation exposure as indicators of barriers, Murray & McMillan used the following statements as identifiers of barriers; "I just don't like doctors or hospitals", "The doctor might think I was bothering him with minor complaints", "The examination and tests might be uncomfortable or painful", "I would be afraid of the findings; if something is really wrong, I wouldn't want to know about it", I would be afraid that I might need to have an operation", "Depending on what was wrong, I might become disfigured from the treatment", "If something was wrong I might become a burden to my family", and "If something was wrong I might become disabled or lose my job" (Murray & McMillan, 1993, p.96).

Other dimensions have been loosely linked to the HBM for the purpose of predicting health behaviour. In a 1989 study, Burack and Liang developed an interview instrument which included measurements of knowledge and utility (Burack & Liang, 1989). Calnan used concern about health, use of dentists, and previous use of breast screening as indicators of Health Motivation, while Murray and McMillan (1993) used participation in 5 activities: physical exercise, improved diet, lost weight, cut down on coffee, reduced alcohol consumption. The variance in these operational definitions supports Kegeles (cited in Calnan, 1984) contention that the HBM lacks a coherent theoretical framework.

McBride, Curry, Taplin, Anderman, and Grothaus (1993) combined the HBM and Social Learning Theory (SLT) (see Appendix A) in a heuristic model. This model was not supported by their data, yet they concluded that it required further testing. Another conclusion would be that it requires modification.

The consequences of this failure to adequately conceptualize, operationalize and validate the constructs that are used to measure health behaviours is reflected in the low predictive power of the models. In 1984 Calnan reported on a study in which the HBM was assessed for prediction of attendance at a mammography clinic or at a class teaching breast self-examination (BSE). The predictive power of the HBM was low, a finding consistent with previous studies. Calnan's (1984) finding that the HBM accounted for little variance between attenders and non-attenders at mammography screening was replicated by Aiken, West, Woodward and Reno (1994). Although the HBM has been used more extensively than other models, its value remains unclear.

Table 1: Constructs Representing Barriers in the Health Belief Model - 9 Breast Cancer Screening Studies

	Study Number								
Construct	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Cost	X	X	X			X			
Inconvenience							X		
Time	X			X					
Need Emergency	X								
Embarrassment		X	X	X					
Confusing									X
Fear		X	X						
False Alarms									X
Fear Radiation		X				X	X		
Don't like Drs			X						
Dr. thinks minor			X				X		
Fear Findings			X	X		X			
Afraid of operation			X						
Disfigure from Rx			X						
Burden to family			X						
Become Disabled			X						
No Regular Dr.					X				
Afraid of Rx						X			

1. Baumann, Brown, Fontana, & Cameron (1993)
2. Zapka, Harrirs, Stoddard, & Costanza (1991)
3. Murray & McMillan (1993) & Grothaus (1993)
4. Champion (1994)
5. Fulton, Buechner, Scott, DeBuono, Feldman, Smith, & Kovenock (1991)
6. Burack & Liang (1989)
7. Aiken, West, Woodward, & Reno (1994)
8. McBride, Curry, Taplin, Anderman
9. Hill, Gardner, & Rassaby (1985)

Failure to clearly conceptualize and validate the constructs which measure health behaviours also plagues the use of other models. For example, Baumann, Brown, Fontana and Cameron (1993), within the context of the Triandis model, describe barriers as constructs that range from social-environmental circumstances to insurance considerations, yet they do not provide theoretical support for the constructs that they use.

B. Cervical Cancer

Although there was a general paucity of literature which used theoretical models and frameworks to describe health behaviours relating to cervical cancer screening, the HBM was the model most frequently used. Two of three articles that cited use of the HBM acknowledged that they had combined dimensions and constructs from this model with those from the Theory of Reasoned Action (TRA) (Hill, Gardner, & Rassaby, 1985; Hennig, & Knowles, 1990) (see Appendix A). Hill, Gardner, and Rassaby (1985) advocate the use of such composite models so that a more comprehensive understanding of health behaviours is obtained. Although the inherent value of comprehensive models of health behaviour can be acknowledged, the validity of these methods for developing such models must be questioned. Hening and Knowles (1990) used the HBM and TRA composite questionnaire developed by Hill, Gardner, and Rassaby to determine it's use as a predictor of intention for women aged 40 and older to have a Pap smear. Even though their findings indicate that the TRA and the HBM only accounted for 12% and 27% of the variance in intentions respectively, the authors state that each model is a significant predictor of intention (Hening & Knowles, 1990, pp. 1612 & 1617). In comparing their results with those of Hill, Gardner, and Rassaby (1985), Hening and Knowles noted that the difference in predictive value of the TRA between the two studies (26% and 12% respectively) may be attributed to the differences in ages of the two study populations; the median age of women in the Hill, Gardner, and Rassaby study was 34 (1985, p.61) whereas Hening and Knowles studied women aged 40 and older. The predictive value of the HBM was similar for both studies. These comparisons indicate that the predictive value of both models was low independent of the populations studied.

The use of theoretical models to design screening programs was described by Palos (1994). In this article he advocated the use of a combination of strategies to influence the cervical screening behaviours of ethnic populations. The program described in this article specifically targeted Hispanic women, particularly those aged 55 and over, living in Texas. Elements of the HBM, Social Learning Theory (SLT), Diffusion Theory (DT), Social Planning (SP), and Social Marketing (SM) were combined to develop a screening program which addressed intrapersonal, interpersonal and community issues for this ethnic population (p. 111). The HBM and SLT respectively dealt with intrapersonal and interpersonal factors that influenced screening behaviours. Although this program was identified as a success based upon the utilization rates, it is unclear what impact each component of the model had on program effectiveness.

C. Prostate Cancer

None found.

D. Colorectal Cancer

Hoogewerf, Hislop, Morrison, Burns and Sizto (1990) studied health belief and compliance with screening for fetal occult blood. These researchers noted that the HBM was not as strong a predictor of compliance as age. The conceptualization of "barriers" in this study and in a study conducted by Price (1993) were again quite dissimilar and thus comparison between studies is not possible.

E. Cardiovascular Risk Factors

Murdaugh and Verran (1987) combined constructs and concepts from the HBM and Social Learning Theory with health value orientation and health care activities to develop the Preventive Health Model (p. 284). They tested and expanded their theory to predict physiological indicants of cardiac preventive behaviours. A small sample of 41 subjects completed questionnaires which reflected concepts associated with three stages and predicted a fourth stage, "physiological health outcomes". In Stage 1 the construct "psychological situation" was measured using concepts related to barriers and benefits of health behaviours. The causal pathways of this model predict that the psychological situation will positively influence expectancy and reinforcement value in Stage 2, behaviour in Stage 3, and thus physiological payoffs in Stage 4. The instruments used to measure the constructs in each of these stages were derived from pre-existing scales and from a review of the literature related to the constructs in each of these stages. Even though a significance level of .15 was used, the concepts accounted for a small amount of the variance in each of the stages and therefore should not be considered predictive of physiological indicants of cardiac preventive behaviours.

Krieidler, Campbell, Lanik, Gray and Conrad (1994) indicate that readiness for behavioural change is not currently being used as a practice and research model in gerontological nursing. These researchers therefore conducted an intervention study which applied the Stages of Change Theory to a blood pressure screening program to determine the role that caregivers might play in facilitating the behaviour change process. The underlying assumption that was made in the conduct of this study was that individuals do not "unfreeze", and thus change their behaviours, until they feel a level of discomfort with their health status. This interpretation of the Stages of Change Theory must be viewed with caution.

F. HIV

None found.

G. STD

None found.

H. Adult Abuse

None found.

I. Child Abuse

None found.

III Summary

The use of theoretical frameworks to describe behaviours is strongly supported (Glanz, Lewis, and Rimer,1989). The use of validated frameworks and models that have been proven to be predictive of behaviours allows researchers to compare data across studies and thus make reliable predictions regarding the factors that influence behaviours. In this way, such frameworks or models can reliably guide the development of policy and programs. Unfortunately, the majority of the research reviewed for this report was either based on the use of models that are not highly predictive of health behaviours or did not use a theoretical framework or model to describe the behaviours that were studied.

The development of a formal theory of preventive health behaviour follows from development of theory in a number of substantive areas (e.g., disease entity, type of test, population characteristics, cultural issues, caregiver characteristics). Formal theories that have been developed in this way will provide a more reliable foundation from which to generate models that predict preventive health behaviours. Some authors (Hill, Gardner, & Rassaby,1985) advocate the use of composite models so that a more comprehensive understanding of health behaviours is obtained. However, if, as with the HBM, studies conducted in a number of substantive areas indicate that the model is not highly predictive of behaviour, it is important to reexamine the theory underlying the development of the model rather than combining it with other models in an attempt to create a new model with greater predictive power.

Section II
Barriers to and Facilitators Of Screening

I Introduction

The purpose of this section is to describe the barriers identified in the published literature and to assess common themes and trends. Factors which influence patient and caregiver related screening behaviours may be viewed negatively as barriers; alternatively, they may be viewed as facilitators when they expedite screening. Lack of income, for instance, may be a barrier but high income could be a facilitator. Barriers to and facilitators of screening behaviours can influence either the patient who must obtain the test, the caregiver who must make the referral or deliver the test, or both. Literature on health behaviour suggests that barriers and facilitators may influence outcomes at two stages: when the intention to act is developed and when the decision to follow through on intentions is made. In addition, barriers or facilitators may operate at the level of individuals or at the systemic level (Mullen, Hersey, & Iverson, 1987; Prochaska & Diclemente, 1986; Salazar, 1991).

This section will look at systemic and personal level barriers or facilitators identified in the literature in nine subject areas and related to patients or caregivers. Caregiver was chosen as a term to represent health care providers as well as people responsible for public education, outreach, and so on. Patient was selected to represent those for whom screening is intended. While some factors act as barriers or facilitators at the level of individuals, they are socially constructed, and therefore included as systemic factors (e.g., attitudes and social support). We initially wanted to review the barriers to intention, followed by a review of barriers to action; however, the literature rarely made this distinction so that approach was abandoned for a more efficient combined review.

A summary of overall findings will complete this section.

II Systemic Barriers to and Facilitators of Intention and Action

A. Patient Related

1. Breast Cancer

Saint-Germain, Bassford and Montano (1993) identifed a lack of social support as a major barrier to screening for older Hispanic women. Social support was seen as essential to facing the personal and social demands of a disease such as cancer. Lack of social support was expressed in procrastination, lack of motivation and not wanting to know if one had cancer. Motivation is closely linked to intention (Calnan, 1984).

Systemic variables affecting patients include: lack of child care, transportantion, and poverty (Black & Ades, 1994). Lack of transportation was cited as a particular barrier for rural women. Working women have identified lack of time and care givers as especially important (Rubenstein, 1994).

Having knowledge of the screening test does not necessarily translate into development of personal intention. Seven US surveys of non-Hispanic white women between 1988 and 1989 found that the most frequently cited reason for not having a mammogram was that they had not thought about it and/or there was no problem. Most of these women had heard about mammography (NCI Breast Cancer Screening Consortium, 1990). A random survey in Ontario also found that 37% of women aged 50 to 69 felt that mammography was unnecessary and 17% felt it was not relevant to them (Perrault et al., 1994). Furthermore, the impact of messages about screening benefits or services decreases if messages are not repeated over time (Rubenstein, 1994).

Fulton et al. (1991) found that rates of screening mammography increased with income. Breast cancer screening rates are lower in poor women in the United States as evidenced by seven National Cancer Institute studies covering various parts of the country (NCI Breast Cancer Screening Consortium, 1990).

2. ***Cervical Cancer***

Attitudes towards Pap tests and perceived social support for this behaviour have been found to be positively associated with the intention to attend (Norman, Talbott, Kuller, Krampe, Stolley (1991). Miller et al. (1991) suggest that young men should be educated to support and encourage screening in their partners, presumably because this would facilitate participation in screening. In addition, they suggest that cervical screening should be encouraged within a framework supporting care for well women and that adolescents should receive education on cervical cancer prevention.

Speaking only or mostly Spanish was associated with not having heard of Pap tests and with lower rates of screening in the previous three years. More Spanish (18%) than English (2%) speakers reported fear or embarrassment as reasons for not having had a test, but over 11% of Spanish speaking women said their doctor had not suggested a test or said it was unnecessary. The authors suggest that inability to speak Spanish may preclude practitioners from conveying the need for the test (Harlan, Bernstein, Kessler, 1991).

Women without health care insurance or who had no usual source of care in the US were less likely to have cervical screening than women with conventional insurance (Kirkman-Liff & Kronenfeld, 1992).

Skubi (1988) studied medical records of Native women on a South Dakota reservation and found that only 37% of women aged 20 to 65 had received a Pap test in the previous two years. He identified 33 patients who had not received diagnosis, treatment or follow-up consistent with the findings of their Pap test.

Barriers associated with this included limited income of patients which precluded them from travelling to the centres where treatment could be obtained. Additionally, serious poverty was postulated to make screening and follow-up a low priority in relation to other stressors.

In a review paper, Norman, Talbott, Kuller, Krampe, and Stolley (1991) reported on several studies which found that white women are more likely to have ever had a Pap test but black and Hispanic women are more likely to have had one within the last 3 to 4 years, even after adjusting for age, education and income. Decreasing income was found to be associated with less chance of ever having been tested and frequency of testing, but more strongly with the latter. Decreasing education was also associated with decreasing testing, but the role appears to be mediated by other factors such as utilization of health services. A study in Manitoba concluded that Pap tests were less likely after tubal ligation, probably because visits to physicians for gynecological reasons had decreased.

3. ***Prostate Cancer***

None found.

4. ***Colorectal Cancer***

None found.

5. ***Cardiovascular Risk Factors***

None found.

6. ***HIV***

Social norms that forbid frank sexual discussions make education around HIV/AIDS difficult.

The potential of breaches of confidentiality is a barrier to HIV screening (Brandeau, Owens, Sox, & Wachter, 1992).

7. ***STD***

None found.

8. ***Adult Abuse***

Social stigma associated with a label acts as a barrier to decisions to seek screening. McLeod (1989) identified being labelled as a battered woman as stigmatizing for women. Women reported feeling different and being treated like victims by professionals. The literature shows that women will answer questions about abuse if asked but they are reluctant to initiate discussion for fear that the caregiver will not believe them, will minimize the abuse, or will think they are to blame.

9. Child Abuse

None found.

B. Caregiver Related

1. Breast Cancer

How public education campaigns are conducted can result in failure to deliver messages to those who may be the most in need. While public education has raised awareness about the need for older women to receive mammography, the message was less likely to have reached women with less education, older women, and women with lower incomes (Rubenstein, 1994).

Significantly different rates of screening in similiar populations using similiar health services implies that systemic rather than patient related barriers are influencing the rates; however, this explanation is often overlooked. For instance, Whitman et al. (1991) looked at the medical records for Pap smear, breast examination and mammography screening rates of African-American women who attended 3 different clinics. One clinic had significantly lower screening rates than the other two. The rates of receiving two screens within the last five years (i.e., a conservative measure of appropriateness of screening protocols) were 16%, 51% and 31%, each significantly different from the other. In seeking an explanation for this, the authors found that the demographics of the patients were very similar but they did not report on the characteristics of the clinic staff or operations. It is noteworthy that the women in this study had frequent access to health care (i.e., an ave of 4 or 5 visits per year). Similarly, Khojasteh et al. (1992) found different patterns of screening in 2 rural clinics after an intervention. Identification of Stage 1 cancers went up with rates of Stage II and III going down at one site and the opposite pattern occurred at the second site. Again, the authors propose to examine only patient characteristics as explanatory factors.

McBride et al. (1993) found that the following environmental barriers distinguished participants and nonparticipants in mammography at a specialty clinic: more than a 20 minute wait; difficulty getting to the clinic; difficulty parking; difficulty with transportation; and poor convenience to the clinic. Aiken, West, Woodward, and Reno (1994) found that cost was a barrier to obtaining mammography but that and having a regular place to obtain medical care increased participation rates. In seven studies in the US, having a regular source of medical care predicted screening in non-Hispanic white women; however, the majority of respondents did have a regular source of medical care. Cost was cited by few women (2% to 13%) as a barrier (NCI Breast Cancer Screening Consortium, 1990). Kiefe, McKay, Halevy, and Brody (1994) found that addressing cost alone was not sufficient to increase mammography attendance.

Black and Ades (1994) identify a number of barriers to cancer screening, including breast cancer, for low income urban populations. These include location, planning and organization, education, and program utilization factors. They involved the community in identification of barriers and facilitators in three Urban cancer

Prevntion and Control Interventions. All three projects experienced cost, inadequate medical resources resulting in long waits and follow-up, lack of accessibility and availability and appropriateness of services, fragmentation of medical services requiring repeat visits by the patient, lack of coordination of medical services resulting in long waits and multiple visits, and lack of knowledge among providers of follow-up issues.

One of the consequences of poverty may be inaccurate address and telephone information on medical records which might be used for recruitment into screening programs (Sung et al., 1992).

Rubenstein (1994) was the only author to mention the need for mammography equipment accessible to women with disabilities.

Older Hispanic women identified the poor communication skills of physicians as problematic. Physicians appeared to lack time to ensure that information was understood and the patients reported feeling like they were not receiving individualized or personal care. Language issues were also a barrier, namely, lack of Spanish-speaking physicians, lack of translators and, related to this, issues of confidentiality. When a translator was used the women could not control the information exchange. Lack of consistency in medical care was a barrier since one would have to repeat one's medical history more than once (Saint-Germain et al., 1993).

2. ***Cervical Cancer***

A national workshop on cervical screening in Canada identified the following systemic related factors which contribute to ineffective screening programs: lack of laboratory staff; and lack of effective quality control in laboratories (Miller et al., 1991). Presumably these factors lead to longer waiting periods for results and inaccurate results which creates problems like unnecessary stress, the need for retesting, missed positives, etc.

Norman, Talbott, Kuller, Krampe, Stolley (1991) found consistent support in 25 years of research for the association between having a regular source of medical care and Pap testing. Seeing a gynecologist is an even stronger predictor. Many women who did not have a Pap test had seen a physician during the time period. Carney, Dietrich and Freeman (1992) found that having a regular health care provider was more important than participation in the education program offered through a women's community screening program. Financial barriers to Pap testing were most frequently cited by participants in the educational program (48%), followed by lack of time (10%) (in the comparison group the rates were 25% and 16% respectively). Harlan, Bernstein and Kessler (1991) found that women whose primary source of care was a Health Maintenance Organization (HMO) were more likely to receive a Pap than those who used a physician's office. However, Lutz (1989) studied HMO users and found that sole female earners were less likely (64%) to receive a Pap test than women in families with a

sole male earner (72%) or families with multiple earners (73%). This would suggest that factors such as availability of childcare, hours of service, sick-leave or physician leave from work, and other contextual factors may impact on attendance.

Spurlock, et al. (1992) found that a family income less than $10,000 was associated with non-attendance in women aged 60 and over.

Spurlock, Nadel, and McManmon (1992) found in a Kentucky population-based survey that doctors never recommending a Pap test; not having a clinical breast exam; never seeing a gynecologist; and never having used birth control pills was associated with not having had a Pap test in all age groups. Never having been married was associated in younger women (aged 16-44), and not belonging to a woman's group was associated with no test in women aged 45 and over.

Arraiz, Wigle, and Mao (1990) recommend that screening be part of an overall prevention program that included primary prevention through smoking cessation and barrier contraceptives.

Marcus et al. (1990) found that a large percentage of unscreened low-income women had received medical care within the previous 5 years. STD clinics and hospital-based emergency care facilities did not give cervical screening priority.

3. *Prostate Cancer*

The effectiveness of prostate cancer screening in reducing mortality is uncertain (Berger, 1993; Littrup, Goodman & Mettlin, 1993). There have been no studies of the diagnostic success rate for general practitioners using Digital Rectal Exam. The most effective screening method or combination of methods has not been established for general population, non-clinical-trial screening (Chodak, Keller & Schoenberg, 1989; Hinman, 1991; Littrup , Goodman & Mettlin, 1993).

4. *Colorectal Cancer*

Colorectal cancer screening is not well established as an effective preventive strategy. Eddy (1990) concluded that no recommendation about colorectal cancer screening can be made. "Any recommendation, whether for a specific screening strategy or for no screening at all, should be considered a guideline, not a standard" (p. 381). However, Wagner, Herdman and Wadhwa (1991) stated that screening is reasonably cost-effective in the elderly and Mandel et al. (1993) concluded that rehydrated annual fecal occult blood testing resulted in a significant reduction (33%) in mortality over 13 years.

Screening tests for colorectal cancer have limited sensitivity and the success of screening depends on the strategy employed by the physician in follow-up. Lieberman (1994) suggests that even if both a sigmoidoscopy and a barium enema are negative, a physician cannot be satisfied and that colonoscopy should be viewed as the first test. A number of issues need further research: can screening be

targetted at high risk patients; appropriate intervals for screening after negative results; which patients would benefit from full colonoscopy; and benefits of subsequent screening.

5. *Cardiovascular Risk Factors*

Workplace screening programs for cardiovascular disease risk factors are popular. Leigh, Guisinger and Fech (1989) identifed several barriers to participation in worksite screening: 1) forgetting time or place; 2) workload demand and an emphasis on productivity precluding attendance; 3) scheduling conflicts with breaks, meetings or heavy workflow.

In order to diagnose hypertension, three readings on three separate days are recommended (Motley, Linder, Crump & Pierce, 1992). A patient will need return visits. The same may be true for diagnosing hypercholesteremia. Thus, screening for these risk factors involves more intensive follow-up and participation than for some other tests.

While several articles support the idea of screening children for CVD risk factors (e.g., Davidson, VanCamp, Iftner, landry, Bradley, & Wong, 1991; O'Brien, 1991; Bush, Zuckerman, Taggart, Theiss, Peleg, & Smith, 1989), other authors (Lauer & Clarke, 1990; Newman, Browner, Hutley, 1990) oppose such screening. This type of CVD risk screening therefore remains controversial.

6. *HIV*

Donovan (1991) reports that family planning clinics in the US give clients basic information to assess their risk. Concern exists among clinic administrators that funding policies around HIV are shifting the focus of clinic programs away from pregnancy prevention.

Ethical issues are raised most often in the literature on HIV screening (e.g., Hamblin & Somerville, 1991; Levine & Bayer, 1989). Mandatory screening of some populations (e.g, some criminals) has been proposed but the justification is often protection of others (e.g., victims of criminal acts or guards), and the medical evidence does not support the value of screening. In fact, the person who fears that they have been infected must ultimately be screened in order to determine if transmission has occurred (Blumberg & Langston, 1991). Individual autonomy and liberty will be jeopardized by mandatory screening since positive results are likely to result in discrimination (Goldberg, 1992).

Screening for high risk behaviours is the first level of screening for HIV testing; however, this is problematic since people with risk factors may be reluctant to identify those behaviours (e.g., needle sharing) (Brandeau, Owens, Sox, & Wachter, 1992) in the face of possible social repercussions.

7. *STD*

Donovan (1991) reports that family planning clinics in the US are seeing patients who are sicker and less likely to have other sources of health care than in the past. Although chlamydia is the most common STD, family planning clinincs were less likely to screen for it than gonorrhea or syphilis. The explanantion for this was lack of financial support for chlamydia screening.

STD clinics are reluctant to introduce Pap screening because of a fear of duplication of services available elsewhere but data show that first-time attenders at a Canadian clinic had not had a test in the previous 6 to 12 months and 11% were found to have abnormal screens (Robertson, Megran, Duggan, McGregor, & Stuart, 1991).

8. *Adult Abuse*

The attitudes of health professionals have been identifed as barriers to screening. Attitudes can cause caregivers to minimize abuse, deny it, or blame the victim (Hanvey & Kinnon, 1993). Little leadership in dealing with wife abuse has been shown by the hospital sector or the public health sector in Canada (Hanvey & Kinnon, 1993). Little published literature exists detailing how to establish a screening program (Lazzaro & McFarlane, 1991)

Women are disadvantaged by race, culture, sexual orientation, and disability when accessing services (Hanvey & Kinnon, 1993). It is proposed that the medical model, where disease is diagnosed and treatment proposed has resulted in a tendency to separate problems from their context and to reduce them to simple cause and effect scenarios. This framework inhibits physicians from assessing the abused adult. Failure to adequately assess the abuse serves to disconfirm the experience and to minimize the consequences.

9. *Child Abuse*

Barriers to screening for child abuse include willingness, training and time availability of staff. Staff fears about the consequence of labelling may limit screening and interventions may be offered to all clients in order to avoid stigmatization (Barth & Hacking, 1986).

As noted by Flynn (1987) the symptoms of child sexual abuse are nonspecific and screening requires special communication and assessment skills. The intervention tasks, once a case is suspected or identified, are more complex than simply prescribing medication. Furthermore, the issue of child abuse is highly emotional; Fontana (1985), for instance states that screening protocols, " allow you to readily spot sexual abuse and rescue a helpless child from an overwhelming ordeal that, unchecked, will inflict permanent physical and psychological trauma" (p. 158). Statements like this may have the opposite affect to inspiring participation.

Child abuse clearly involves other systems outside of the health care system. Social and political factors lead to confirmation of cases; for example, whether a case is labelled substantiated by the justice system may depend on the perceived seriousness and types of maltreatment (Giovanni, 1989). Hansen, Diamond and Ludwig (1989) describe three cases where inaccurate diagnosis by physicians, poor risk assessment by child protection, and overruling of the pediatrician's recommendation by the family court judge resulting in death or severe disability in the child. Lack of coordination of systems has been frustrating for many professionals.

III Personal Barriers to and Facilitators of Intention and Action

A. Patient Related

1. Breast Cancer

A study by the American Association of Retired Persons found that 74% of those surveyed in 1992 had seen or heard a message about older women needing mammograms, thus public knowledge has been improved.

Several studies have found that previous attendance at breast screening was predictive of attendance at a screening clinic (Calnan, 1984; Fulton et al., 1991, McBride et al. 1993).

McBride et al. (1993) found that four beliefs held by women about mammography served as barriers to attendance at screening: "a) pain and discomfort associated with the procedure; b) fear of finding cancer; c) the need for symptoms before obtaining a mammogram; and d) the benefits of mammography for early detection of breast cancer" (p. 600). Rubenstein (1994) also reported fear of cancer and embarrassment as barriers for older women. In an Ontario study, 26% of women aged 50 to 69 were fearful of finding cancer (Perrault et al., 1994). Few women (1% to 10%) in seven US surveys of non-Hispanic white women between 1987 and 1989 identified fear of radiation as a barrier to mammorgaphy (NCI Breast Cancer Screening Consortium, 1990), compared to 29% of women in a 1993 Ontario study (Perrault et al., 1994).

The extent to which a person controlled or expressed anger, depressed mood or anxiety (measured by the Courtauld Emotional control scale) was not related to BSE or attendance for cervical screening (Murray & McMillan, 1993).

Beliefs about one's susceptibility to breast cancer compared to other diseases are positively correlated with attendance at mammography screening (Aiken, West, Woodward, Reno, 1994); however, seven other US studies found that history of breast cancer in a mother, sister, or daughter was only weakly associated with recent breast screening (NCI Beast cancer Screening Consortium, 1990). Black and Ades (1994) found that denial, fatalism, fear of cancer, low education level, and beliefs in myths about cancer were barriers to use of screening.

2. *Cervical Cancer*

Hill, Gardner and Rassaby (1991) found that beliefs that the Pap test provided a sense of relief, detected early cancer that was curable, and reasurred the patient were positively associated with intention to be screened. Embarrassment, worry about results, and finding the test unpleasant had a negative association.

One study found that beliefs and attitudes about the procedure and possible outcomes predicted participation in cervical screening, namely, dislike of doctors and hospitals; worrying that the doctor would judge complaints as minor; embarassment by the tests; fear of results, of needing an operation, or of being disfigured by surgery; fear of being a burden on the family; or fear of becoming disabled or losing their job. Women who perceived the fewest barriers were most likely to attend (Murray & McMillan, 1993). A study in British Columbia in Native women also found that lack of knowledge of Pap tests and their importance and feelings of embarrassment and shamefulness were reasons for not attending (Deschamps et al., 1992). A study of Hispanic migrant farm workers found that the women avoided screening due to embarrassment and shame and discomfort with male clinicians (Lantz, Dupuis, Reding, Krauska and Lappe, 1994). Perceived susceptibility to cervical cancer, belief in the efficacy of Pap tests, and fear of finding cancer predicted screening. Women aged 65 and older were less likely to have a Pap test, as were less educated and unemployed women. Older women tended to perceive themselves as less vulnerable to cancer (Lerman, Caputo, & Brody, 1990).

The extent to which a person controlled or expressed anger, depressed mood or anxiety (measured by the Courtauld Emotional control scale) was not related to attendance for Pap screening (Murray & McMillan, 1993).

Misunderstanding the purpose or importance of the test; fears of embarrassment, pain or of the results are negatively associated with attendance. Psychosocial variables such as depression, alienation, or powerlessness have not been found to be associated with having a Pap test (Norman, et al. (1991)

3. *Prostate Cancer*

Few studies were found that discussed the social attitudes or norms that may impede men from seeking preventive care. A number of gender specific attitudes and beliefs were identified in one study which would serve as barriers to forming an intention to seek screening. Men said that they were not interested in the issue of prevention and would not discuss symptoms when ill because of fears of appearing vulnerable. Some men expressed pride in the length of time that they had avoided a doctor and men tended to believe that health naturally deteriorated with age. Men passed responsibility for their health to the women in their lives, relying on them for information and making appointments, but at the same time they proposed that health messages should stress maintenance of independence and not becoming a burden to family members. The men identified conflicting information in the media as a reason for ignoring all information. It was also noted

that men are less likely than women to attend courses (Rubenstein, 1994). In another study men who believed that their "health was too good to even think about the possibility of getting prostate cancer" (p. 31) were less likely to have been screened (Millon-Underwood,1992).

4. Colorectal Cancer

Lantz et al. (1994) also found that social attitudes prevented men from seeking care. Migrant farm workers alluded to not wanting people to see one as weak; as "a woman" (p. 516), for seeking medical examinations. There was general discomfort around discussing the digital rectal exam, and again, a statement that men do not like that part of their bodies to be viewed.

Price (1993) surveyed 500 low SES (annual household income $18,000) residents of Ohio concerning colorectal cancer. The main barriers to screening identified were: not having enough money (53%); transportation (81%); not wanting to know if they had cancer (78%); embarrassment over coloscopy (77%); would rather die than lose bowel (80%). It was also interesting that 22% of respondents believed that homosexual men were more likely to develop bowel cancer and 55% thought that Blacks were most likely to get bowel cancer.

Hoogewerf et al. (1990) found that confidence about being able to take a sample predicted compliance with an HOII kit. Confidence that an ulcer would not change their lifestyle was another important factor, and being too busy was a reason given by about 25% of noncompliers. In a review of the literature, Winawer, Schottenfeld and Flehinger (1991) found that patients who complied with colorectal cancer screening were more likely to have positive attitudes towards preventive health practices, to have more contact with medical services, and to be less frightened of cancer.

5. Cardiovascular Risk Factors

None found.

6. HIV

Stigmatization of and discrimination against homosexuals is a barrier to HIV testing. Misconceptions that the virus is limited to homosexuals has interfered with prevention.

7. STD

Cultural factors that prevent open discussion of STDs permits misinformation to abound. Further, patients may be reluctant to discuss STDs with physicians due to a fear of confidentiality. Beliefs that people who get STDs are unclean also serve as barriers to screening as individuals do not wish to be identified with stigmatized groups (Moy & Clasen, 1990).

In a study of male college students, Kaplan, Meyer and Navin (1989) found that 20% had chlamydia but were asymptomatic; therefore they would not have sought screening. The same is true for men seeking screening for other STDs (Reitmeijer et al. 1991). Personal inability to face the consequences of an STD is another reason identifed for not seeking screening (Moy & Clasen, 1990).

8. Adult Abuse

Over a third of women with a past history of abuse indicated that they preferred a female provider; however, only 13% of women currently in an abusive relationship stated a preference (Sampsell, Petersen, Murtland & Oakley, 1992).

9. Child Abuse

Identification of adult survivors of childhood sexual abuse may be important in clinical care of psychological as well as physical conditions. Adult survivors, however, may be reluctant to disclose to a health care provider for the following reasons: fear that they were at fault; shame, a feeling of unworthiness or sinfulness; a fear that others will be repulsed or shocked; fear of being betrayed or hurt; gender of the therapist. Janikowski and Glover (1994) found that 64% of clients undergoing treatment for substance abuse would discuss incest issues if asked by their counselor. Shame and fear of a breach of confidentiality were most frequently cited as reasons for not discussing incest. Other factors included painfulness of the subject (34%), lack of trust (30%), belief that counselling wouldn't help (31%), or that counseling was not needed (30%).

B. Caregiver Related

1. Breast Cancer

A study by the American Cancer Society (1990) found that factors affecting physician referral rates included: perceived reliability of the test; support from the National Cancer Organization for the screening protocols; increased incidence of the disease; and patient receptivity to testing. While intention to refer was not specifically the outcome of interest, these factors seem likely to affect behaviour at that level.

Physician factors related to referral to mammography screening were studied by Schoen, Marcus, and Braham (1994) using retrospective chart review of 261 patients in an internal medicine clinic of a teaching hospital. Data available on physicians included: year since graduation and gender. Physicians were more likely to refer women who had a previous history of breast cancer or who were generally in good health. Residents in their first year were more likely than those in their 2nd or 3rd to refer. Physician gender did not predict referral practices. In a series of focus groups, older Hispanic women identified that their physicians put dealing with their chronic illnesses ahead of recommending screening (Saint-Germain et al., 1993).

A survey of nurse practitioners found that four common reasons for not implementing cancer screening protocols were: practice setting constraints; not feeling competent; lack of time; and cost. Physicians in a national survey also mentioned cost, but the top reason for not following guidelines was disagreement with them (Warren & Pohl, 1990).

Having one's physician recommend breast screening is one of the key facilitators to women's behaviour yet physicians often fail to make this recommendation or referral. In one study, 92% of women aged 50 and older who were first degree relatives of women with breast cancer had not been referred for mammography. In another, less than half of the women (44%) had received a recommendation for mammography from their physician (Zapka et al.,1992). Aiken, West, Woodward and Reno (1994) found that physician recommendation of a mammogram was the single most important predictor of attendance, accounting for 25% of variance between groups of attenders and nonattenders. Factors from the HBM accounted for an additional 10% of variance. Zapka et al. (1992) also found that physician recommendations improved mammography screening rates; however, they found that patients of gynaecologists and internists were most likely to have had a mammogram. Kaplan et al. (1991) found that nearly twice as many women who saw a gynaecologist as a general practictioner received a mammogram. Similarly, Fulton et al. (1991) used the HBM to study mammography screening in Rhode Island women and found that physician recommendation of mammography had the greatest independent effect (OR 18.77) on screening status. The second factor was having visited any provider for gynaecological care in the previous year (OR, 4.92).

2. *Cervical Cancer*

A national workshop on cervical screening in Canada identified the following individual related factors which contribute to ineffective screening programs: lack of training of physcians; and lack of follow-up for detected abnormalities (Miller et al., 1991).

Norman, et al. (1991) reported on several studies that found that a doctor's recommendation for a Pap test was very influential. In one study, no elderly women refused a recommended test.

Cockburn, Hirst, Hill, and Marks (1990) identifed the need to integrate Pap screening into the regular process of general-practice consultations. Furthermore, firm appointments to return for Pap tests must be made to encourage women to follow-up with recommendations from general practitioners (Norman et al., 1991).

Lack of continuity of care contributes to a failure to inform women of results and of the next date for the annual check-up (Deschamps et al., 1992).

3. *Prostate Cancer*

None found.

4. *Colorectal Cancer*

None found.

5. *Cardiovascular Risk Factors*

In an Australian study, Heywood, Ring, Sanson-Fisher, and Mudge (1994) found that doctors identified few patients with self-reported risk factors: 66% of smokers; 40% of heavy drinkers; and 59% of overweight patients. Only 51% of patients had had a cholesterol screen in the past 5 years but 90% had had blood pressure screening. Blood pressure is taken by the physician and had the highest compliance, which the authors propose is because it takes little time, provides immediate feedback, and is non-intrusive. In addition, effective drug therapy is available and the physician sees immediate results which are not dependent on the patient's behaviour, such as dieting or exercising. While cholesterol screening takes little time, it is more intrusive for the patient, has additional associated cost, and may not be seen as an efficacious screening tool.

6. *HIV*

Fear and confusion surrounding HIV have led healthcare providers to call for mandatory testing of patients; however, Unkle (1990) notes that mandatory testing could lead to a false sense of security where strict guidelines for safe clinical practice should be maintained.

Nahmias and Feinstein (1990) state that the benefit of screening and case detection cannot be assessed until policies are in place "to exploit the identification of infected persons so as to reduce the spread of the virus" (p. 253). Levine and Bayer (1989) maintain that there is insufficient evidence of either successful prevention of transmission or treatment methods to justify mandatory screening.

7. *STD*

None found.

8. *Adult Abuse*

Health care providers often hold the false belief that wife abuse is uncommon in higher SES groups (Sampsell, et al., 1992).

Some medical staff , regardless of institutional protocols or training programs, do not see adult abuse as a medical concern (Hendricks-Matthews, 1992). Kurz, 1990) and therefore do not intend to screen.

Physicians express frustration and strong emotion associated with this subject. Some identify the time required to do an assessment as a barrier. Denial, rationalization and minimalization are also barriers reflective of societal attitudes (Bishop & Patterson, 1992; Hendricks-Matthews, 1992; Illnicki, 1994). A survey of family physicians revealed the following barriers to dealing with abuse: "lack of knowledge of available resources; time constraints of running a practice; restrictions in training; futility with respect to the women's compliance; and being unable to interrupt the cycle of violence" (Illnicki, 1994, p. 12). Time constraints was mentioned most often (26%) (Illnicki, 1994). Nurses also may operate under the misconception that their intervention will result in the woman leaving the abusive marriage; however, the process of leaving often takes years and the nurse may feel frustrated, angry, or like a failure when she sees that the woman has returned (Lazzaro & McFarlane, 1991). If not addressed, this may result in a reluctance to do further screening.

In a study of the responses to battered women by staff in four hospital emergency departments, Kurz (1990) found that staff modified the degree to which they responded based on whether they perceived the woman to have stigmatizing traits (e.g., alcohol on breath, reluctant to talk, acts "inappropriately") or whether they saw abuse as a priority of their medical role.

9. Child Abuse

Identification of child abuse by health providers requires attention to symptoms that are often vague and only indicative of problems when they occur in combination, are persistent, or are severe. Nurses and health care providers may react to child abuse with anger, frustration, denial, and confusion (Stanley, 1989), strong feelings that may interfere with their ability to use screening protocols.

IV Summary

A. Variability in the Literature

The literature from 1990 to the present was uneven in terms of the extent to which barriers in the nine areas of screening were addressed. Inevitably, there are articles that refer to barriers but which do not have key words or MESH headings that would have been picked up in our search. However, there are a number of reasons why the literature is uneven. Breast cancer screening, in particular mammography screening, is well-established and has received a great deal of attention in recent years as reflected in the greater proportion of articles on the subject. Pap screening has long been established and population screening rates are quite impressive so that attention can turn to reaching those who have been missed. Continued attention is directed at improving program effectiveness and keeping screening rates high. Consensus on effective screening protocols for prostate cancer and colorectal cancer remains elusive; therefore, it is not surprising that little literature existed addressing barriers to screening. The overriding concern in HIV screening appears to be the ethics of screening when social discrimination can occur simply from having the test, and will certainly occur if one is revealed to have had

positive findings. There was little literature on barriers to screening for STDs and given the prevalence of these diseases, one can only speculate that they enjoy less public support than a disease like cancer and, therefore receive less research support. Child abuse screening, like Pap screening has a well established history. The authors are aware of a larger body of knowledge in this area than was identified by our search strategies; however, the general issues identified in the few articles that specifically addressed screening represent the key issues. Abuse of adults, particularly wife and elder abuse, is not well established as a health care screening issue though recent initiatives by the Federal and some Provincial governments has contributed to the subject being added to some health curricula. As with prostate and colorectal screening, therefore, it is not surprising that there is little literature on barriers to screening.

B. Common Themes

While it sometimes appears that barriers to screening vary by screening behaviour (Murray & McMillan, 1993) a number of similarities exist. First, professionals must be convinced that tests are acceptable and valuable before they will consider using them. They must then be knowledgeable about tests and screening protocols and skilled in administering tests. The complexity of the screening procedure is therefore a potential barrier to professional utilization. Regardless of the issue, the protocol must fit into regular practices or routines; time is an important issue for health professionals and for patients. This may account for the higher screening rates of women who are seeing gynecologists. There is some evidence that preventive screening will be placed second to addressing the health concerns or problems that a patient presents with (e.g., diabetes, pregnancy, etc.); however, since having a regular source of medical care is clearly facilitative of screening, over time the doctor may get around to fitting in preventative tests. One study found that women who got Pap tests were more likely to have had mammograms and vice-versa (Kirkman-Liff & Kronenfeld, 1992).

The organization of the health care system and of units within the system clearly impacts on screening. Waiting periods vary for appointments for tests, for getting results, and for follow-up testing or treatment. Location of services affects accessibility. Living in an area where one cannot establish a regular caregiver precludes benefiting from that relationship. Specialization results in a narrow focus (e.g., STD clinics not doing Pap screens), and one type of provider may assume that another is screening the patient.

The traditional model under which physicians have been trained, the medical model, does not encourage health care providers to screen for problems that the physician cannot "fix" (e.g., child abuse, wife abuse, smoking, alcohol abuse, overweight, etc). Further, since fear, shame and embarrassment are associated with a majority of the tests, the caregiver needs excellent communication skills. The need for different models of doctor-patient communication has been identifed by a number of writers and researchers. Nurses and other health care providers are also criticized for not communicating effectively with users of the health system (e.g., Batt, 1994). Attention must be paid, however, to all players in the communication

process. Several studies found that people did not know about screening tests and the health care encounter may not be the most appropriate time to gain an understanding of the test, its merits, risks, etc. Other people knew about tests but did not know if they needed the tests; they waited for physcians to prescribe. Attention to patient responsibility for their own health care, and communicating needs to caregivers is therefore important, keeping in mind the power dynamics in these relationships.

Fears about loss of confidentiality were associated with many tests and point to a level of distrust of the system. In general, research has found that the Canadian and US public trusts physicians and hospitals (Louis Harris & Associates & Westin, 1992). There is clear evidence that fear over privacy of medical records exists and the European experience has been that legislators have acted to severely restrict access. Screening research will be somewhat dependent on use of disease registries, case and control identification through medical records, and other access to information which may be highly sensitive. Public mistrust may increase if adequate protection is not in place and perceived by the public to be effective (Thurston, Burgess & Bischoff, 1995).

Social support appears to play many roles in screening. Support for the importance of the test is an important motivator, and evidence that many people have had a test may increase its social acceptability and lessen embarrassment. Social support may mediate difficulties such as lack of child care, transportation problems, or other accessibility barriers. In addition a social network may provide the information about when, where or how often to get a test, interpretation of results, and so on. Furthermore, social support may mediate fear of diagnosis or that one could not cope with bad news.

The appearance that barriers vary by screening behaviour may be contextual, for instance, some barriers may be more prominent at different points in the history of a screening behaviour. In addition, barriers to intention may differ from barriers to action for the same behaviour. Screening tests for which evidence of efficacy is unclear are more likely to be seen as not worth the trouble. For some cultures language of service will be a problem, but this will not be true for all minorities.

C. Systemic Versus Personal Barriers

The majority of issues that appeared frequently and across screening protocols require solutions at the social or systemic level rather than programs directed at individuals; for instance, poverty, transportation, child care, lack of time, organization of services (location, knowledge, skills and attitudes of staff, language in which services are available), having a regular health care provider, and priority given to preventive health care. Personal level issues that could be handled with public education or one on one by health care providers include: fear of results, knowledge of tests, shame and embarrassment, and taking an active role in pursuing screening.

Little of the research that was reviewed was Canadian. This may present a problem in interpretation of some findings since the majority of the research is from the United States which has a very different health care system. This has implications, however, for how the Canadian system is restructered in the current age of health "reform".

There were few articles that compared the barriers to different screening behaviours. It was most common for similarities in barriers to different screening tests to be examined in the breast cancer and cervical screening literature. In that literature, however, it is unusual to find studies that compare associations between Pap or breast screening and other preventive health behaviours (Norman, et al., 1991).

Section III
Interventions

I Introduction

A number of efforts to improve the rates of screening have been made. This chapter will identify some of the interventions described in the published literature which are aimed at patients and/or caregivers in each of the nine subject areas. Strengths and weaknesses of the interventions will be identified where possible. The summary will present an overview of the chapter.

II Patient and Caregiver Related

A. Breast Cancer

Rimer (1994) reviewed the literature describing interventions to increase mammography screening rates. She classified interventions in the following way:

1. Individual directed interventions, e.g., mailed reminders and telephone counselling
2. System-directed and physician-directed interventions, e.g., computerized or manual prompting and reminder systems
3. Access-enhancing interventions, e.g., mobile vans or the provision of transportation to appointments
4. Social network interventions, e.g., peer-group leaders
5. Multi-strategy interventions using combinations of the above. (p. 324)

She identifies several studies that found statistically significant improvements in attendance after the interventions. Figure 1 briefly describes the types of interventions and the degree of success mentioned. None of the studies cited by Rimer appeared in our search on barriers which suggests that the word barriers was not used in abstracts or as a key word. This may mean that the authors were not using a theoretical framework of preventive health behaviours to guide the interventions. Overall, the gains in mammography screening rates were modest (i.e., 15%, 12%, 28%) even if fairly intensive interventions were employed. For instance, one program included physician-directed interventions, the provision of free mammograms, annual packets to women along with mailed reminders and telephone counselling and resulted in a 12% difference between the intervention group and the control group. In other reports that Rimer considered successful, it was not possible to assess the gains because control groups rates were not reported. No report of cost-effectiveness was included in this review.

Zapka et al. (1993) used a physician intervention that included a series of in-services on breast examination and other skills needed, periodic newsletters, a supply of patient education materials, and aids and forms for practice management. Education for women was held periodically in the community using a number of strategies. Breast cancer screening rates improved in both the intervention and the control communities, but there was no difference between the communities after three years either in mammography or breast clinical exam rates.

In one project 52 physicians in a university general medical practice were interviewed regarding 7 cancer screening tests. They gave 4 reasons for not screening: their objections to the test; forgetfulness; lack of time; and patient dislike of the test or refusal; thus physician objections to screening appeared to play as great a role as patient concerns. In order to increase physician use of 7 cancer screening tests, 62 internal medicine residents were randomly assigned to one of six intervention groups: 1) audit of previous 9 months, individual feedback and invitation to 5 educational luncheons; 2) receipt of a cancer screening reminder at each patient visit which listed appropriate tests based on patient sex and age, recommended testing intervals, last performance date, and current "due" status; and 3) control or no intervention. Within each of these groups, half of the female patients received a letter and pamphlet on professional breast examination and mammography. One finding was that physicians overestimated the rate at which they ordered all tests compared to actual charts; for instance, mammography self-report 49%, chart 23%. Audit with feedback increased compliance with mammography and breast examination, stool occult blood tests, and rectal exams when preintervention compliance was controlled. Cancer screening reminders increased compliance with all tests except Pap smears. Patient education only improved compliance for mammography in physicians who received cancer screening reminders (McPhee, Bird, Jenkins, Fordham, 1989, p. 1868).

Some papers attribute success to certain interventions but provide little detail upon which to make an assessment. Rubenstein (1994) mentioned using volunteers to teach BSE, using Native women to teach BSE to Natives, using volunteers to provide information on low cost screening facilities through a toll-free telephone, and sponsoring free mammography in low income areas.

Figure 1: Summary of Types of Interventions and Results from Rimer (1994)

Attribution-based messages to women over 40 heightened their sense of personal responsibility for mammography, 12 month screening rates improved

Mailed reminders and interactive telephone counselling, women aged 50 to 60, 3 fold increase in attendance (base rate not specified)

Mailed reminders and telephone counselling for nonadherent women, physician-directed interventions, free mammograms over 3 years, 12% difference between intervention and control women

Recommendation letter and postcard reminder, doubles odds of attendance (less success for women who lived 45 minutes away, in poor health, or smokers)

Telephone counselling and personal letter, 14% increase over control (access problems had lower rate)

Physician-directed interventions, community campaigns, cost reductions over 3 years. 25% increase in intervention community, 10% increase in control

Mobile van, reduced costs, community-wide education, mailings to individual health centre clients, 28% increase in participation

Physician education and practice outreach with community interventions to encourage women to request mammography, 8 fold increase in physician orders for mammograms

Use of nurse practitioner, 22% increase

Health education messages tailored to those over 65, lowered price, mobile van, 33% increase over control

Use of culturally sensitive women in community institutions and clinic waiting areas to recruit, 8% increase

B. Cervical Cancer

An 18 month intervention with poor African-American women included having nurse clinicians and public health workers recruit women in public clinics and community institutions (Ansell, Lacey, Whitman, Chen, & Phillips, 1994). A computerized data base was developed for each screening program site and extensive training ensured quality of care from the nurses. Letter reminders were generated 2 weeks prior to appointments. Letters describing recommended follow-up or test results were also generated. A nonintervention control was selected for each clinic. Awareness of the free screening program at the community control clinic increased by 24% and awareness at the intervention clinic increased by 26%. Both of these are statistically significant results but clearly the intervention was not more successful than doing nothing. Awareness at the intervention hospital increased significantly (8%) but there was no increase at the control hospital. Black and Ades (1994) reviewed several demonstration projects intended to increase screening especially for the socio-economically disadvantaged and underserved. They recommend seven successful strategies; employing outreach staff indigenous to the community, deliver education through existing programs rather than stand-alone; incorporate cancer information and issues with more relevant community issues; develop culturally and community specific materials; keep messages simple; be positive about people's ability to affect health; and emphasize wellness and health, not cancer and fear.

Sung et. al. (1992) trained lay community health workers to recruit low-income inner-city black women to screening programs. Less than half of those asked to participate did so. The authors conclude that greater attention must be paid to developing successful intervention strategies.

C. Prostate Cancer

Martin (1990) described a quasi-experimental study in which male employees of a large company in the southwestern United States participated in an educational program regarding prostate cancer. The program provided information related to health behaviour values and beliefs, disease-specific information, as well as information regarding risk factors and screening techniques. Pre and post-intervention questionnaires which measured knowledge were completed by 566 and 571 employees respectively. The majority of the participants were under 40 years of age, white, married and had high school educations. Although the difference in pre and post-intervention scores was statistically significant to the 0.01 level, this study did not measure behaviour. There is no evidence to support the assumption that increased knowledge resulted in improved screening behaviours.

D. Colorectal Cancer

Nurses delivered one of three colorectal cancer education interventions to elderly people participating in a state meal program: using elderly people as teachers and demonstrators; using learning methods appropriate to the age group recognizing

such things as short term memory loss; a combination of the previous two; "Traditional method or control method" (p. 324). The latter were not described. Hemoccult II testing kits were given to each participant. The combination method had the best results; however, the actual screening rates are not given (Weinrich, Weinrich, Boyd, Johnson, & Frank-Stromborg, 1992).

Public service announcements, articles for the mass media and information over medial information services were used to increase knowledge about the importance and means of screening (Molgaard, Ryden, Robin, Gresham, Elden & Scutchfield, 1990). They did not measure improvement in screening rates. Knowledge of the disease and screening measures improved but misconceptions regarding the disease (e.g., whether colostomy was necessary) continued.

E. Cardiovascular Risk Factors

Community health workers were trained to provide information about blood pressure treatment and care to patients in an emergency department who had been found to have high blood pressure. Follow-up was stressed and patients were given a wallet sized blood pressure record card. Patients were phoned (at least three attempts were made) to remind them of their follow-up appointment. The telephone reminder resulted in a 19% increase in attendance. It is not clear from the report whether every patient received each part of the intervention. The control group appears to be those patients whom it was not possible to contact.

Linnan, Gans, Hixson, Mendes, Longpre, & Carleton (1990) report on the training and success in use of volunteers to carry out education and counselling on risk factor screening in the Pawtucket Heart Health Program.

Cowell, Montgomery and Talashek (1989) concluded that after eight years of school-based health education the prevalence of cardiovascular risk in sixth grade students had not declined. Screening was part of the program.

People who are told that they are high risk after the initial screen appear to be more likely to follow-up (Gordon, King & Whelton, 1990). However, it would be unethical to use this information as an intervention to increase follow-up. It may be that how the message is delivered to people affects rates of follow-up.

F. HIV & G. STD

A private hospital in Texas implemented a hospital wide voluntary screening program for HIV seroprevalence (Harris, Boisaubin, Salyer, & Semands, 1990). A special consent form was developed and patients could get more information from health care providers. About half of patients voluntarily underwent screening. The program provided no assistance to program planning for prevention of nosocomial infections and, although the authors conclude that it was beneficial to patients this evidence is not clear. Twelve false positives resulted and 15 true positive were identified. One case where the consent process was breached was documented.

Another Texas project used identification of the sites where high risk behaviour occurred to increase screening for STDs and HIV (Hutcheson, et al., 1993). A team visited the 21 sites and obtained specimens on site, ensured treatment for those with exposure to or infection with an STD, and collected data necessary for follow-up. Two physicians in private practice in the affected communities provided medical care and testing and cooperation with the social service and community-based organizations was established. Several previously unidentified cases were identified. Compared to a similar project in Philadelphia where loss to follow-up was 33%, the rate in this project was 1%. Success was attributed to the innovative outreach methods as well as maintaining good relations with the target community .

H. Adult Abuse

None found.

I. Child Abuse

None found.

III Summary

This was not intended to be a comprehensive review of intervention studies. As discussed under breast cancer screening a number of intervention studies did not show up in our literature search, presumably because they did not use barriers as a key word. This may indicate that they were not using a theoretical framework. Indeed, few of the articles reviewed above mentioned a theoretical framework or model. Very few papers reported on interventions directed at caregivers. Many studies evaluated success in knowledge change as opposed to screening behaviour.

The most outstanding similarity is the low to moderate success rates of interventions. Multi-strategy interventions did not appear to do much better than single interventions. Secondly, many studies involved interventions required large allocations of resources which may not be feasible in many settings. Few process evaluations were reported. In combination with outcome evaluations, process evaluations help to assess the generalizability of any program. There was some evidence to suggest that involvement of the target community and community organizations increased success and sustainability. This is the approach advocated by health promotion.

Section IV
Methodological Issues

I Introduction

Health care research involves a process of identifying the questions to be answered, selection of a design that will provide the necessary data with a minimal expenditure of resources, interpretation and dissemination of results, and application of research to practice. This chapter will describe strengths and limitations in identification of research questions in the screening literature. General issues related to research design, including sampling biases, issues around operationalization of variables and implementation of research design will be discussed. The role of evaluation research will be described.

II Research Questions

Much of the research that has attempted to identify barriers to screening has focused on barriers at the individual level. Despite the evidence that systemic barriers have a major impact on an individual's ability to participate in screening, very few studies have examined systemic characteristics. Although cost of screening, lack of access, and lack of time off work have been identified as barriers to screening (Lantz, 1994; Rubenstein, 1994; Saint-Germain, Bassford, & Montano, 1993; Skubi, 1988), few studies examine the socio-economic factors that underly these barriers. Furthermore, no studies were found that looked at the determinants of physician behaviour, including systemic determinants, although the lack of referral to screening by a physician has repeatedly been identified as a barrier (Costanza, Stoddard, Zapka, Gaw, & Barth, 1991; Harlan, Bernstein, & Kessler, 1991). Very little knowledge of the factors that influence physician behaviours, and thus enhance physician compliance with screening guidelines, is evident in the literature on screening. The continuing medical education literature would be a source of such information. Similarly, discussion of the impact of other health care providers was missing.

Other systemic factors that have received little attention and which need clarification involve cultural norms, attitudes and values or ethics. Perceptions of appropriate behaviours for males, for instance, may preclude their attendance at screening. Community attitudes towards discussion of sexuality issues may make some screening tests more sensitive than others (e.g., cervical, prostate, or HIV). Papers discussing the ethics of screening practices were pretty much limited to the topics of HIV/AIDS. In another subject area, one paper suggested intervening with women in order to get their partners to screening. While this may sound like an appropriate intervention, the ethics of increasing womens' responsibility for the health care of others needs to be discussed.

Research questions must be developed around the interpretation of correlations and the meaning of relationships. In fact, the actual construct represented by a certain measure should be made clear and this is only possible if the theoretical framework has been established. For example, Kirkman-Liff and Kronenfeld (1992) indicated that lack of insurance coverage was a major barrier to screening. They stated that "uninsured women and women with no usual source of care" (Kirkman-Liff & Kronenfeld, 1992, p. 734) were less likely to participate in screening programs than women with conventional insurance. It would be inappropriate to assume that lack of insurance was the major reason for this population's failure to comply. People who are uninsured may also have concerns regarding securing adequate food, housing, and childcare that may supercede their interest in participating in screening programs. Skubi (1988) also suggested that screening for cancer was a low priority for a population of women who faced socioeconomic stresses such as poverty, substandard housing and unemployment. Lutz (1989) indicated that women who were the primary wage earners for a family were less likely to participate in screening programs despite their membership in an HMO. The barriers to screening for such individuals are obviously more that just access and insurance coverage or the cost of the service.

Some research questions are simply overlooked. For instance, there are few studies of the role and impact of other care providers (e.g., Does having a nurse in the practice or clinic significantly increase the chances of screening taking place?). In intervention studies where multiple interventions are employed, few look at incremental increases produced by each intervention. If decision makers have to drop one aspect of the multiple intervention, they would need this information to decide which it would be. Related to this is an absence of cost-effectiveness or cost-benefit studies.

Studies that find success in attendance for screening using multiple interventions to recruit subjects, maintain their involvement and encourage screening behaviour may have little practical utility because most settings will lack the resources to replicate the interventions. The question of sustainability of programs is another one that has been overlooked. This is naturally related to the issue of cost, but also to issues of program development and community ownership.

III Research Design

A. Sampling Biases

A problem with many studies of utilization of breast cancer screening is that they include only white, middle-class (well-educated) women with relatively easy access to medical services (Aiken, et al., 1994; Baumann, et al., 1993; Zapka, et al.,1992). The latter study included women aged 35 to 92 (mean 55.4 sd13.4). Such biases are also evident in studies of cervical cancer screening (Hennig & Knowles, 1990; Hill, Gardner, & Rassaby, 1985). In other studies, the failure to clearly identify the demographics of the study sample limited the interpretation and

generalizabilty of the findings (Gregorio, Lolachi, & Hansen, 1992; Houlston, Murday, Harocopos, Williams, & Slack, 1990). This is important when subjects are selected from health care services because these samples are inherently biased.

B. Operationalization

The lack of adequate conceptualization and operationalization of the constructs used to measure health behaviours may contribute to the deficiency in the number of studies that have demonstrated a significant level of variance attributable to the constructs being studied (Aiken, et al., 1994; Fulton et. al, 1991; Burack & Liang, 1989; Hening & Knowles, 1990).

Aiken, et al. (1994) identified 12 studies that addressed predictors of screening mammography. They indicated that all six of the cross sectional studies that they reviewed had used the "criterion of *ever* having had a mammography ... [which] may have weakened the relation of health beliefs to mammography screening"(p. 123). They recommended that current compliance be measured by two factors: a) date of most recent mammogram and (b) age (Aiken, et al., 1994,). Only in this way is it possible to determine whether the woman is practicing age appropriate screening behaviours.

In intervention studies, operationalization of outcomes is important. In some instances researchers have suggested that screening utilization may be enhanced by addressing access issues and increasing screening knowledge in patients (Ansell, Lacey, Whitman, Chen & Phillips, 1994). Although such studies have tended to correlate increased knowledge with increased participation in screening programs (Kriedler, Campbell, Lanik, Gray, & Conrad, 1994), they have either only measured screening behaviours immediately following an educational intervention (Weinrich, et al., 1992) or they have not measured screening behaviours at all and have assumed that knowledge change will predict behaviour change.

C. Implementation

Part of the process of health care research involves the implementation of research strategies that provide the required data with a minimal expenditure of resources. Studies that identify success in overcoming barriers to screening through the implementation of multiple intervention strategies to recruit subjects, maintain their involvement and encourage positive health behaviours (Sung et. al., 1992) will prove to be of little utility in practical settings because of resource requirements.

D. Selection of Methods

Shiffman et. al. (1991) cite the following methodolgical advances that have, and may continue to, increase the sophistication of health behaviour research: a shift in the unit of analysis from the individual to the group; using self-report of behaviours to validate biochemical data; increasing the length of follow-up to validate reports of behavioural change; the use of more sophisticated statistical techniques; conducting evaluations of processes as well as outcomes to develop a greater understanding of all stages of behaviour change. Bloom (1994) supports the recommendations of Shiffman et. al. (1991) and supports our contention that research should be driven by theory and include the roles of the system, the provider, and the individual.

Specific analytical recommendations are provided by Aiken, West, Woodward, and Reno (1994) who advocate the use of a hierarchical analysis procedure in which health behaviour predictors are systematically entered into the analysis and thus the predictive value of each variable is more accurately assessed. Fulton et. al. (1991) suggest that prospective studies, although more expensive, may provide a better understanding of the relationship between health beliefs and behaviours.

IV Evaluation Research

The use of both process and outcome evaluation research will better inform the development of successful intervention strategies. Whereas outcome evaluations tend to dominate the literature, the strength of such methods is limited by the validity of the constructs that are used to measure success. Process evaluation, although underutilized, can prove to a be valuable method to reveal how well a program was implemented according to plan, and what needs to be done to improve the program (Halvorson, Cohen, Brekke, McClatchey, & Cohen, 1993). Shiffman et. al. (1991) advocate a continued shift toward the inclusion of process evaluations in behavioural research in the prevention and early detection of cancer.

Reports of evaluations done over the life cycle of programs are needed in order to disseminate knowledge about program development issues and generalizability of programs. Blackwell and Cartwright (1988) identify four program life stages: 1) the preliminary plan or idea; 2) the new or early program; 3) the life stage where an impact is starting to be seen (middle); and 4) the mature program. Appropriate evaluation questions and designs vary by life stage of the program. Too often, outcome evaluations are undertaken before the program has been well implemented (stages 1 and 2) and the bugs worked out.

V Summary

This analysis of methodolgical issues highlights several recommendations that may enhance the field of research on health behaviours. It is essential that clearly defined research questions be identified to examine barriers at a systemic as well as an individual level. To overcome sampling biases more support must be provided to studies which examine disadvantaged populations and in this way build on the substantive research that has been completed on white, middle class people. Clear and consistent operationalization of constructs is required to enhance the validity and reliability of the constructs and thus improve the generalizability of health behaviour research. This implies that there is a need for qualitative research that will build a body of substantive theory on which to develop formal theory related to health behaviours. The research methods that are selected must be such that the recommendations for intervention programs can be feasibly applied in practical settings. The multi-dimensional nature of health behaviours requires that the research that is conducted in this area be of a multi-disciplinary nature.

Section V
Future Research Needs

I Introduction

This chapter will identify where research is needed specific to the findings of the previous chapters.

II Theoretical Models or Frameworks

Much can be learned from the field of health promotion about theory, models and frameworks (Pederson, O'Neill, Rootman, 1994). Primary, secondary and tertiary prevention have traditionally been focused on disease and risk as established by epidemiological assessment. The concept of primary health care, which is closely aligned with the development of health promotion, pushed health care professionals to look more broadly to behavioural and social epidemiology. Health promotion, however, has tended to focus on the importance of resources for achieving or controlling health at either the individual (e.g., coping skills) or the community level (e.g., infrastructure, esprit). Health promotion, therefore, is linked to all three levels of prevention and can inform preventive practice (Thurston, 1991). Health promotion is defined by the World Health Organization (Epp, 1986) as the process of enabling people to increase control over and to improve their health. Prevention programs that decrease control would therefore be questionable within the health promotion framework.

Attending for screening is one of many health enhancing behaviours. Health promotion requires that health behaviour be viewed in the context of everyday life. According to the Ottawa Charter for Health Promotion (1986) the determinants of health are: peace; shelter; education; food; income; stable eco-system; sustainable resources; and social justice and equity. Models of health behaviour have tended to view behaviour in a reductionist paradigm with the assumption that behaviour is rational; therefore, if a person is told that a test will reduce their chances of dying from a given disease, rationally they would be expected to have that test. Despite evidence that these models fail to explain much of behaviour (e.g., Health Belief Model), they continue to be used, although not well. The relative importance of the determinants of health needs to be assessed; for instance, despite knowledge that one in ten women living with a man is abused by him, the impact of this lack of peace, justice and equity is not raised in the breast and cervical screening literature. Further, since health promotion emphasizes building the capacity of individuals and communities to improve and control their health, it can reframe the view of individuals at high risk as part of a "target group" to seeing them as part of a community of interest. For instance, Hutcheson et al. (1993) went to the "community" of intervenous drug users and, working with them, achieved a much higher screening rate than other programs.

We saw no reference to theoretical models of health care professional behaviour although one of the major barriers to screening is lack of recommendation from a physician. Furthermore, there is evidence that preventive health behaviour is considered secondary to tertiary care by most health professionals. It is simplistic to believe that knowledge improvement will change patient behaviour, and the same is true about changing health care provider behaviour.

In order to build theory, coordinated research across substantive areas is needed. Further more, the multi-faceted nature of health behaviour requires that multidisciplinary research advise the development of effective intervention strategies. Expertise in theories of communication or social change, for instance, may be needed by those designing interventions once the barriers to screening have been explicated.

III Major Gaps in Knowledge

A. Theory

Although many researchers modified or combined models, we did not discover any research that was designed to test the validity of the models. The application of newer models (e.g., Stages of Change, Triadic Influence) is needed and the basic research to identify constructs and to test the validity and reliability of measures is needed. This work needs to be done for many reasons including the need for a better understanding of the mechanisms through which barriers affect attendance at screening and to inform effective intervention strategies.

Multidisciplinary research is required since social and psychological theories of change are clearly important.

B. Health Care System

Canadian based research was particularly scarce. Certainly much can be learned from research in other countries; however, since the majority of the barriers are systemic and the Canadian and US health care systems currently differ, some research needs to be done within the Canadian social context. Although failure to prescribe and to adhere to screening was related to cost of the test in several US studies, we cannot be sure that those factors would play as much of a role in Canada. Of course, given the restructuring of the health care system that is occurring across the country, the relative influence of some factors may change. In fact, this restructuring may provide a natural experiment and an opportunity to study the impact of some systemic factors on screening tests.

C. Populations with Unique Needs

There was no research addressing the needs of disabled women and specific barriers they face. This is not because there are no differences; for instance, the researchers are aware of research indicating that women with disabilities are four times as likely as other women to be sexually abused. One author noted that women with physical disabilities would have difficulty obtaining a mammogram.

Although there was some research on Black and Hispanic women in the US, there was virtually no research on other racial and ethnic groups. The need for multicultural health care has been recognized in many centres and it is important to recognize the cultural beliefs that may act as barriers or facilitators to screening (Masi, Mesah, McLeod, 1995).

D. Explication of Barriers

No barrier to screening is well explicated in the literature. Failure to use theoretical frameworks, to replicate findings and to do studies in different populations and locations accounts for this. We do not understand the role of education level, income or social support. It is possible that citing transportation as a barrier is actually a statement about income that may or may not be ameliorated by public transportation. If one has no disposable income then even the cost of public transportation is prohibitive. And a lack of child care may be indicative of poor social support. One study, (Saint-Germain, Bassford, & Montano, 1993) found that personal semi-structured interviews led to a different interpretation of barriers than that provided by a survey. Barriers must be understood at all phases of screening: recruitment, retention, follow-up, or subsequent screening. There was a dearth of research, for instance, that differentiated people who were regular versus first-time attenders at screening. Although previous Pap or mammography screening was predictive of future screening whether this was explained by personal (e.g., greater comfort with the test) or systemic (e.g., having a regular physician who tests) variables was not reported.

IV Methodological Considerations

A. Asking Relevant Questions

This is closely related to the issue of developing and using theoretical frameworks. However, a tendency to overlook the importance of systemic variables was identified; for instance, different screening rates between clinics may be accounted for by the behaviour of health care professionals in the clinics or by contextual factors, rather than by the characteristics of the patients. Use of models to explain the behaviour of health professionals is essential, and these must include models of diffusion of practice preferences as well as explanations of their own participation in screening.

A key issue in understanding barriers may be avoidance of socially acceptable responses. Saint-Germain, Bassford and Montano (1993) touched on this issue when they compared interview to survey responses regarding barriers. It may be that some people prefer to cite transportation as a barrier rather than admitting lack of money, or to say that a test is distasteful rather than admitting lack of knowledge of a test that is granted importance by virtue of being included in a survey.

B. Sampling

Many studies were limited to samples of white middle class people. This introduces a number of biases that restrict generalizability of findings, and contributes to failure to explicate the interactions and meaning of certain barriers. Studies of physicians routinely obtain return rates that make them virtually useless. Rather than accepting return rates of 10% to 30%, methodologists must investigate cost-effective strategies to obtain more satisfactory and representative samples.

Definitions of race, ethnicity or culture and operationalizations of these constructs must be made clear if studies of immigrant and ethno-racial populations are to have any value. Classifications used in some US studies, such as "non-Hispanic white", have little interpretability from a cultural point of view and may even obscure differences. Expertise has been developed in Canada in this subject area (e.g., Edwards, 1992).

C. Use of Appropriate Methods

A range of methods and designs will be needed to answer the research questions that arise from this review. If one wants to assess the prevalence of a barrier in a population, a well constructed survey is an appropriate choice of method. If one wishes to understand the meaning of barriers in people's lives than a phenomenological study would be more appropriate. Epidemiology has been slow to embrace qualitative research as an acceptable paradigm and this may account for the dearth of qualitative studies in this subject area. For the development of theory, qualitative methods are essential.

Designs must vary according to the purpose of the evaluation of an intervention. When outcome or impact assessment is the goal, several evaluation studies have illustrated the importance of control groups to control for maturity. Reports of success in studies where a pre-and post-test design is used can be interpreted only with caution and are limited in value because we cannot assess how much of the change would have occurred with no intervention. Campbell and Stanley (1966) provide a thorough review of quasi-experimental designs that may be used in evaluation research.

D. Evaluation Research

Most evaluations reported focused on impact assessment. Many, however, measured change in knowledge rather than behaviour when behaviour change was the predicted outcome. Consistency between evaluation objective and methods is needed. Process evaluation is essential to articulating interventions and identifying the extent to which they are generalizable to other sites. Pilot testing and formative evaluation are also needed to refine interventions and clarify implementation strategies.

V Summary

The many gaps in knowledge of screening behaviours provide an abundance of research opportunities. Collaboration across disciplines is essential, and the success of partnerships and collaboration is partially dependent on the development of effective communication strategies (e.g., multidisciplinary conferences or workshops). To ensure development of effective and efficient intervention strategies it is essential that a coordinated national research agenda be developed. A national research agenda will emphasize the need for theory-driven, culturally sensitive research that incorporates the appropriate use of methods and encourages multi-disciplinary collaboration.

Section VI
Summary of Recommendations for Canadian Research

I Introduction

Through this review of literature it was possible to identify gaps in the existing body of research related to screening and thus identify priorities for future research. The following summary of recommendations addresses substantive, methodological and administrative issues to provide general guidelines for future action.

II Substantive Priorities

A. Develop and test a model or models of screening behaviour recognizing the unique characteristics of the behaviour(s) and phases of screening (recruitment, return, follow-up, subsequent screening) and the sociocultural and systemic variables that act as modifiers.

The following is a list of potential sociocultural and systemic variables that have largely been neglected in the existing research on screening. The order of items does not reflect an attempt to designate priority. Potential research projects could examine the influence of:

- communication / language barriers (i.e., caregiver communication style influencing the disclosure of abuse);
- participant knowledge of screening techniques;
- the knowledge and attitude of caregivers;
- employer support for participation in screening;
- social support in screening;
- poverty and screening behaviour;
- accessibility of screening programs;
- availability of screening programs;
- cost to the participant;
- transportation;
- planning, organization, and coordination of services on screening behaviours;
- having regular medical care;
- the availability of accessible, affordable quality childcare; and
- the effectiveness / reliability of the screening test.

B. Other potential research topics include:

- the effectiveness of worksite and school screening programs;
- ethical implications of screening related to HIV and STDs;
- systemic and intra/interpersonal factors that influence the effectiveness of public education;
- assessment of the impact of health care restructuring on screening rates and comparative studies to identify systemic barriers; and
- administrative and methodological requirements for effective multidisciplinary research.

III Methodological Priorities

The effectiveness and appropriateness of research that addresses screening is highly dependent upon the methods that are employed. Methodological imperatives include:

- involvement of stakeholders, including consumer groups in the research process;
- the use of qualitative methods to develop theory and to explicate constructs;
- the use of multidisciplinary teams;
- focusing research on systemic barriers faced by populations that have not been studied (i.e., disabled people, natives, immigrants and refugees, rural populations); and
- design and evaluate intervention studies based upon explicit logic models.

Evaluations should proceed through formative, efficacy and effectiveness assessments and process and summative evaluations should be included.

IV Administrative Principles

Implementation and completion of effective research requires ongoing administrative support. Recommendations related to administrative support include:

- the establishment of a coordinated program of research so that projects can build on each other to develop formal theory;
- the provision of support and encouragement for collaboration between multidisciplinary research teams;
- produce and disseminate guidelines for research on how to ensure adequate response / participation rates among physicians; and
- produce and disseminate guidelines for researchers on collection of ethnocultural data.

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Appendix A
Theoretical Frameworks and Models

The Health Belief Model

The Health Belief Model (HBM) was developed in the 1950's to describe and predict specific health actions of individuals. It originated within the U.S. Public Health Service in response to the growing number of individuals who were not accessing screening and early detection programs that were inexpensive or free of charge.

The model derives from psychological and behavioural theory. Based upon this model, the determinants of behaviour depend on two primary variables: (1) the value placed by an individual on a particular goal and (2) the individual's idea of the likelihood that a given action will achieve that goal (Janz & Becker, 1984).

Specifically, the HBM consists of four fundamental dimensions.

Perceived susceptibility. This dimension refers to an individual's subjective perception of their person risk of contracting a condition.

Perceived severity. This dimension refers to the feeling one has of the consequences of contracting the disease or condition.

Perceived benefits. This refers to the perception that the recommended health action is feasible and effective.

Perceived barriers. This refers to the negative or deleterious effects of a particular health action perceived by an individual.

The following factors may modify these dimensions:

Demographics. This refers to the indirect effect age, gender, race and ethnicity have on the likelihood of taking action.

Sociopsychologic. This variable includes the effect of social/peer groups and socioeconomic status.

Structural. This refers to the individual's knowledge of the disease or prior contact with it.

Cues to action. This includes the internal and external forces that can impact health seeking behaviour.

Janz, N.K., & Becker, M.H. (1984). The health belief model: A decade later. Health Education Quarterly, 11(1), 1-47.

Stages of Change Model

The Stages of Change Model was developed following a meeting of a group of researchers, theorists and therapists in 1984. These individuals met to attempt to develop a comprehensive model of change to be applied to the treatment of addictive behaviours. The three dimensional model that evolved following this meeting integrates *stages, processes, and levels of change*.

The four *stages of change* are: precontemplation, contemplation, action, and maintenance. It is common for individuals to progress in a cyclical pattern through these stages with repeated revolutions required before maintenance is achieved.

The *processes of change* focus on events and activities that may successfully modify behaviour. The processes of change as described by this theory include: consciouness-raising, self-liberation, social liberation, counterconditioning, stimulus control, self-reevaluation, environmental reevaluation, contingency management, dramatic relief, and helping relationships.

The *levels of change* dimension is represented by a hierarchy of five interrelated levels of psychological problems addressed in treatment. The are: 1) symptom/situational, 2) maladaptive cognitions, 3) current interpersonal conflicts, 4) family/systems conflicts, and 5) intrapersonal conflicts. The deeper levels in the hierarchy are further removed from awareness and thus require more complex therapy.

To summarize, this transtheoretical approach combines application of the processes of change at four stages of change according the client's identified problem level.

Prochaska, J.O., & DiClemente, C.C. (1986). Toward a comprehensive model of change. In W. Miller & N. Heather (Eds.). Treating Addictive Behaviours. NY: Plenum

DiClemente, C.C., Prochaska, J.O., Fairhurst, S.K., Velicer, W.F., Velasques, M.M., & Rossi, J.S. (1991). The process of smoking cessation: An analysis of precontemplation, contemplation, and preparation stages of change. Journal of Consulting and Clinical Psychology, 59(2), 295-304.

Social Learning Theory
(renamed Social Cognitive Theory)

Social Learning Theory (SLT) purports that behaviour is a function the subjective probability that an action will achieve and outcome (*expectancies*) and the subjective value of that outcome (*incentives*). Behaviour is regulated by *incentives* as they are interpreted and understood by the individual.

Expectancies are of three types:

1. Environmental expectation or how events are connected.
2. Outcome expectation or the consequences of one's actions.
3. Self-efficacy or one's competency to influence outcomes.

Rosenstock, I.M., Strecher, V.J., & Becker, M.H. (1988). Social learning theory and the health belief model. Health Education Quarterly, 15(2), 175-183.

Theory of Reasoned Action

This model is based on the assumption that humans usually behave in a rational manner, that they take account of available information and implicitly or explicitly consider the implications of their actions. The theory posits that a person's intention to perform or not to perform a behaviour is the immediate determinant of that action. The longer the time interval between the development of the intention and the execution of the behaviour, the greater the likelihood that unforeseen events will produce changes in intentions. Therefore, predictive accuracy will usually be inversely related to the time interval between the measurement of intention and the observation of behaviour. The performance of an intended behaviour may be influenced by characteristics of the individual such as general ability to exercise control over actions, locus of control, skills, information, power of will, emotions and compulsions.

Ajzen, J. (1985). From intentions to actions: A theory of planned behaviour. In J. Kuhland & J. Beckman (Eds.), Action-control: From cognitions to behaviour, (pp.11-39). Heidelberg: Springer.

The Theory of Triadic Influence

The Theory of Triadic Influence (TTI) offers predictions about how constructs from other theories of behaviour are inter-related and offers a detailed description of the processes by which they contribute to health behaviours. Although, specifically developed to address behaviours associated with substance use, the TTI has implications for other health behaviours.

The theory is based on three streams of influence.

Social/Normative Influences. These originate in the intimate social network of the individual and culminate in the individual's normative beliefs.

Cultural/Attitudinal Influences. These originate in the general cultural environment and culminate in the individual's attitudes, expectations and evaluations as they relate to physiological, legal, financial and social consequences of an action.

Intrapersonal Influences. These encompass inherited dispositions, personality characteristics, affective states and behavioural skills which contribute to skills and self-efficacy.

TTI recognizes the existence of both intrastream and interstream pathways of influence.

Flay, B.R., & Petraitis, J. (1993). The theory of triadic influence: An integrative model of substance abuse. Unpublished manuscript.

Appendix B
Search Codes Used For The Review of The Literature

The following search strategies were used to identify the literature used in this review.

The terms "screening" and "early detection" were entered in combination with "barriers or limitations" for each of the diseases or conditions that were included in this report. In addition, the terms "screening protocols" and "health behaviours" were searched separately in each database.

These search strategies were utilized in the following databases: Medline (Medical and Health Care), Sociofile (Sociology), Cinahl (Nursing and Allied Health), Health (Health Administration), and CancerLit.